

FINAL

Virginia Genetics Advisory Committee
Tuesday, October 4, 2011
10:00 a.m. – 12:00 Noon

Division of Consolidated Laboratory Services
Training Room T-23
600 North 5th Street
Richmond, VA 23219
Telephone (804) 648-4480

MINUTES

VaGAC Members (check = present):

- | | |
|--|---|
| <input checked="" type="checkbox"/> Willie Andrews, DCLS | <input type="checkbox"/> Sara Long, MOD |
| <input checked="" type="checkbox"/> Arti Pandya, VCU (Interim VaGAC Chair) | <input checked="" type="checkbox"/> Jana Monaco, Parent |
| <input type="checkbox"/> Tia Campbell, DOE | <input type="checkbox"/> Walter Nance, VEHDIP Adv Cmt |
| <input type="checkbox"/> Eileen Coffman, CHKD | <input type="checkbox"/> William Owen, EVMS/CHKD |
| <input checked="" type="checkbox"/> Karen Durst, VDBHDS | <input checked="" type="checkbox"/> James Pearson, DCLS |
| <input checked="" type="checkbox"/> Laura Duncan, VCU | <input checked="" type="checkbox"/> Ginny Proud, CHKD |
| <input checked="" type="checkbox"/> Tom Hickey, DCLS | <input type="checkbox"/> Charlie Stevenson, DCLS |
| <input type="checkbox"/> Anil R. Kumar, VCU | <input checked="" type="checkbox"/> Bill Wilson, UVA |

VaGAC and Subcommittee Staff:

- | | |
|---|--|
| <input checked="" type="checkbox"/> Kathleen Moline, Staff - VaGAC & Steering Cmt | <input checked="" type="checkbox"/> Jennifer Macdonald, Staff – NBS Subcmt |
| <input checked="" type="checkbox"/> Tiara Green, Staff - BDP Subcmt | <input checked="" type="checkbox"/> Rafael Randolph, Staff - VaGAC |
| | <input checked="" type="checkbox"/> Lillie Chandler, Staff |

VaGAC Ad Hoc Members:

- | | |
|--|---|
| <input type="checkbox"/> Joanne Boise, VDH | <input type="checkbox"/> Ruth Frierson, VDH, VEHDIP Adv Cmt |
| <input type="checkbox"/> Joan Corder-Mabe, VDH | |

Additional Subcommittee Members / Interested Parties:

- | | |
|---|--|
| <input type="checkbox"/> Rachel Arculin, Parent | <input checked="" type="checkbox"/> Valerie Luther, Partnership, VCU |
| <input type="checkbox"/> Stephen Braddock, UVA | <input type="checkbox"/> Paula Miller, Parent |
| <input type="checkbox"/> Heather Bryant, DCLS | <input checked="" type="checkbox"/> Phil Poston, DCLS |
| <input type="checkbox"/> Bonny Bukaveckas, VCU | <input type="checkbox"/> Nicole Safina, CHKD |
| <input type="checkbox"/> Tahnee Causey, VCU | <input type="checkbox"/> Ramona Schaeffer, VDH |
| <input type="checkbox"/> Ning Chen, VCU | <input type="checkbox"/> Alice Schroeder, Parent |
| <input type="checkbox"/> Justin Crow, VCU | <input type="checkbox"/> Cliff Schroeder, Parent |
| <input type="checkbox"/> Yasser El-Gohary, VCU | <input type="checkbox"/> Heather Trammell, Parent |
| <input checked="" type="checkbox"/> Sarah H. Elsea, VCU | <input checked="" type="checkbox"/> Susan Ward, VHHA |
| <input type="checkbox"/> Vicki Hardy-Murrell, Parent | <input type="checkbox"/> Joe Schmidt, M.D., VCU |
| <input type="checkbox"/> Jane Juusola, VCU | <input type="checkbox"/> Cynthia Epstein, M.D., EVMS |
| <input type="checkbox"/> Rees L. Lee, M.D., NMCP | <input type="checkbox"/> John P. Osborn, M.D., FNA |
| <input type="checkbox"/> Deborah K. Froh, M.D., UVA | <input type="checkbox"/> Beth Harkness, RN, BSN, CNMC |

Guests: Dr. Anne Comeau, New England Group & Massachusetts NBS; Barb Ballard, Wei Zhao, Jane Juusola, Andrea Ferreina-Gonzalez, Katie Langley, Susan Tlusty, Veronica Kirkland, Susan Ward

Recorders: Rafael Randolph and Jennifer Macdonald

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1. Welcome: W. Andrews & A. Pandya
 - a. Introductions: Completed
 - b. Minutes of 04/05/2011 Meeting: Approved as written.
 - c. Agenda: No changes
 - d. Membership
 - e. Travel Reimbursement Reminder (members only): Travel Reimbursement forms will be emailed to members.
2. Public Comments: A. Pandya
 - a. None
3. Presentation on Severe Combined Immune Deficiency (SCID): Dr. Anne Comeau
 - a. Presented a power point presentation entitled “NBS for SCID: Experience in Massachusetts”, which was an overview of SCID data, how SCID markers are tested in the laboratory, defining cut-offs, Massachusetts’s experience in bringing stakeholders to the table and follow-up procedures.
 - b. Dr. Anne Comeau believes SCID is the ideal condition to be addition to the newborn screening panel.
4. Review of VaGAC Infrastructure, if needed. K. Moline & J. Pearson
 - a. It was announced that there were no guidelines for electing a new chair in the Infrastructure.
 - b. J. Pearson raised the question – why are they not called bylaws? He also suggested looking at other organizations that had bylaws in place and bringing them to the members of the committee for approval.
 - c. Dr. Arti Pandya has volunteered to be the interim chair while this process is worked out.
5. Subcommittees and Group Reports
 - a. Newborn Screening Subcmt: W. Andrews
 - (1) Cystic Fibrosis/DNA Update
 - (a) Second tier DNA testing at DCLS has a target start date of November 1, 2011. Analysis will occur weekly and include approximately 80 samples. Last steps in process are computer system validation and establishing new f/u algorithm.
 - (2) Other Subcommittee Updates
 - (a) Letter of recommendation for the addition of SCID to the Virginia NBS panel was set forth to the full VaGAC for approval to send to the Commissioner of Health for consideration. This is a new process for us. The subcommittee recommends to the full committee, the full committee upon approval recommends to the Commissioner of Health, and then the Commissioner of Health recommends to the Board of Health. The recommendation for SCID was approved with no nays.
 - b. Birth Defects Prevention Subcmt: T. Green/T. Taylor
 - (1) Tiara Green is no longer the Chair of the Birth Defects Prevention Subcommittee, as the VDH Preconception Health Coordinator. As a result of the OFHS reorganization, she is now the Sickle Cell Program Coordinator. A wage person will be hired as the Preconception Health Coordinator and become chair. Prior to the change two teleconferences were attempted and only three people showed interest in future meetings. Tiara Green suggested that the goal of the subcommittee be evaluated and rewritten to coincide with the name.
 - c. VDH Contractors Ad Hoc Work Group: K. Moline
 - (1) Kathleen Moline stated she was in a new role as the Program Manager of the Newborn Screening Program. A site visits to VCUHS-MCV was conducted and future visits to EVMS and UVA are in the plans.

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6. Updates: Agencies and Organizations

- a. VDH: Office of Family Health Services (OFHS): K. Moline
 - (1) Division reorganization is almost completed and VNSP has not been affected.
 - (2) The first step of VNSP regulation is complete. Regulation changes made by initial group were reviewed by the Board of Health (BOH) and placed on town hall for public comment. There were no relevant public comments. Currently, regulation review is in the 2nd stage. The Board of Health meets in December to formally adopt regulations to send to executive level and then will be placed back on town hall for another comment period.
- b. VDH: Virginia Newborn Screening Program (VSNP): K. Moline
 - (1) Kathleen Moline introduced herself as the VSNP program manager and spoke of her prior experience as a neonatal nurse, came to the Virginia Department of Health as a perinatal nurse consultant, also worked as a policy analyst, before accepting her current position. Currently, VSNP has initiated hospital site visits to two hospitals and the program website has been updated.
 - (2) The Newborn Screening and Genetics Symposium November 7-10, 2011 will be attended by Tom Hickey & Phil Poston (DCLS) as well as Jennifer Macdonald (VDH).
 - (3) Created a website supported by Virginia Alliance called "Baby's First Test".
 - (4) In the process of hiring another follow-up specialist.
- c. VDH: Virginia Early Hearing Detection and Intervention Program (VEHDIP): R. Frierson
 - (1) No update.
- d. VDH: Virginia Congenital Anomalies Reporting and Education System (VaCARES): R. Randolph
 - (1) No update.
- e. VDH: Division of Women's and Infants' Health (DWIH), Preconception Health: T. Green/T. Taylor
 - (1) Tiara Green has been working with Willie and Tom from DCLS to update the Joint Operating Procedure (JOP) with VDH for adult screening within the health departments. The update will allow the Virginia Sickle Cell Awareness Program (VASCAP) to track the number of adults tested, number of abnormal results, age, race and gender to evaluate the program.
- f. VDH: Children with Special Health Care Needs Program (CSHCN), including Care Connection for Children (CCC) and Child Development Clinics (CDCs): Vacant Position
 - (1) No update.
- g. Division of Consolidated Laboratory Services: J. Pearson
 - (1) DCLS is looking to expand their molecular testing area.
- h. March of Dimes: S. Long
 - (1) No update.
- i. Virginia Department of Behavioral Health and Development Services (VDBHDS), Part C of IDEA: K. Durst
 - (1) Has been working with Department of Medical Assistance Services (DMAS) in the past year to receive coverage through Medicaid for direct services for children with disabilities.
 - (2) Also has been working with DMAS relating service coordination.
 - (3) Still searching for a state representative coordinator.
- j. Virginia Deaf-Blind Project: V. Luther
 - (1) At the last meeting it was reported that Fred Orelove was retiring June 30th and a national search was conducted to find a replacement. A replacement was found and transitional meetings with Fred Orelove were being held. Two weeks before the new executive director was supposed to start he informed Fred Orelove that he would not be accepting the position. Senator Harkin from Iowa asked him to take lead on the IDEA Reauthorization, an offer he could not refuse. The university announced that Donna Gilles, Associate Director, would be the Interim Director and a new search would be done next year.

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- k. New York-Mid-Atlantic Consortium (NYMAC) for Genetic and Newborn Screening Services: A. Pandya
 - (1) No update.
 - l. Virginia Association of Genetic Counselors: T. Causey
 - (1) No update.
 - m. VEHDIP Advisory Committee: A. Pandya, W. Nance, and/or R. Frierson
 - n. HRSA Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC): J. Monaco
 - (1) Jana Monaco gave a review of the 25th meeting, which was a review/update of the committee's accomplishments. Dr. Howell has stepped down and a new chair was named. Other items discussed were the addition of testing for critical congenital heart disease to the newborn screening panel.
 - (2) In regards to congenital heart disease testing, Kathleen Moline will bring data back to committee on congenital heart disease for further discussion on committee/health department's roles in the implementation.
7. Updates: Virginia Genetics and Metabolic Centers
- a. Eastern Virginia Medical School (EVMS): G. Proud and W. Owen
 - (1) EVMS is actively recruiting for a geneticist as Dr. Nicole Safina has resigned.
 - b. University of Virginia (UVA): B. Wilson
 - (1) In partnership with Dr. Deborah Froh, a small educational grant has been acquired and some funds will be utilized to educate providers in the state on the 2nd tier cystic fibrosis testing that will start November 1, 2011.
 - c. Virginia Commonwealth University (VCU): L. Duncan and Arti Pandya
 - (1) Dr. Joann Bodurtha has resigned and started her new position at John Hopkins as of October 1, 2011. Dr. Margie Jaworski is working part-time on the team now and a new medical director will start October 17, 2011.
8. New Business: A. Pandya
- a. None
9. Next Meetings: A. Pandya
- a. VaGAC Meeting
 - (1) Date: April 17, 2012
 - (2) Time: 10a.m. – noon
 - (3) Place: DCLS
 - b. VaGAC Steering Cmt Conference Call
 - (1) Date: TBA
 - (2) Time: TBA
 - (3) Place: TBA
10. Adjourn: A. Pandya
- a. Meeting adjourned at 12:20p.m.